Institutional aspects: What are the institutional actions to promote data sharing?

Christine Balagué
Vice president Digital National Council

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CNNum
Conseil National du Numérique

www.cnnumerique.fr

What is the digital national council?

CNNum
Conseil National du Numérique

Taking into account digital metamorphosis on society, economy and public action

❖ **The French Digital Council (CNNum) is an independent advisory commission**. Its remit was redefined and expanded by presidential decree on 13 December 2012, following its presentation on 12 December to the Council of Ministers by Fleur Pellerin, Minister Delegate with responsibility for SMEs, Innovation and the Digital Economy. The Council's members were appointed on 17 January 2013 by presidential decree.

❖ The Council issues **independent opinions and recommendations on any question relating to the impact of digital technologies on economy and society.** The government can consult the Council on new legislation or draft regulations.

❖ **The Council's thirty members come from across the digital spectrum, and include researchers and activists**. The Council organizes public consultations at both local and national level, and is in constant contact with France's digital ecosystem, including elected officials, members of civil society, researchers, digital experts, entrepreneurs and professional organizations.

Members representing digital ecosystem and elected persons

- **A representative council, 50% women/ 50% men:**

  30 members (15 women + 15 men)

  Start upers, researchers, experts, companies CEO, etc.

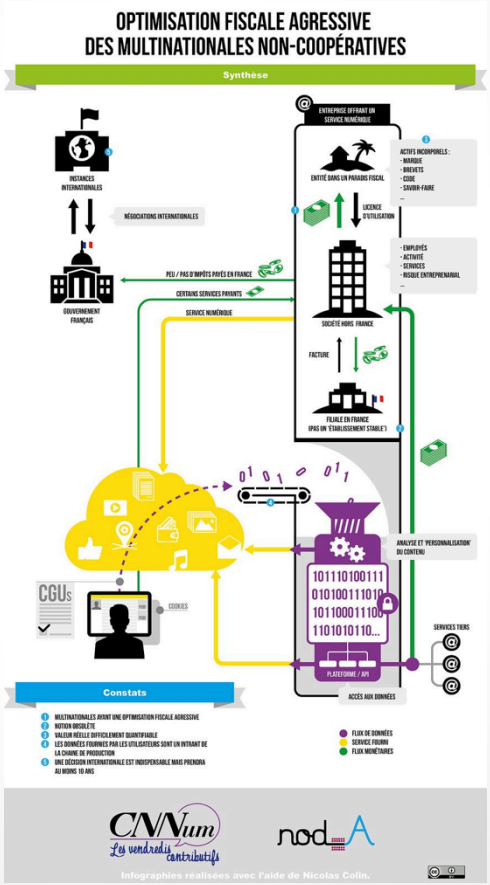
  Decisions votes in plenary sessions

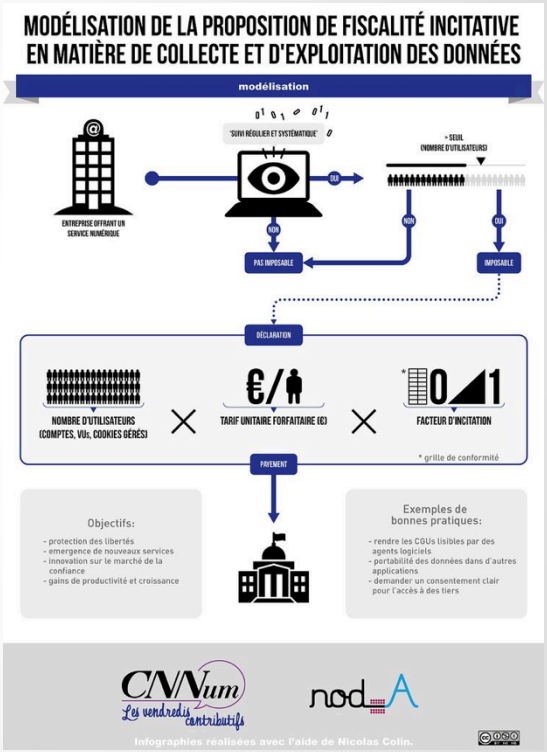
- **Relay for parliament and local collectivities**

  9 associate members, selected in both parliament assemblies

  Deputies, senators, local communities representatives

Methodology: open consultations and the Fridays contributive approach





Reports

- E education: Jules Ferry 3.0, nov 2014
- Opinion n°2014-3 on article 9 on law project against terrorism
- Platforms neutrality, june 2014
- TTIP, may 2014
- Unlawful contents and behaviors, december 2013
- Digital freedoms, december 2013
- Digital inclusion, november 2013
- Digital tax system, september 2013
- Computer science education, june 2013
- Net neutrality, february 2013

Forthcoming:

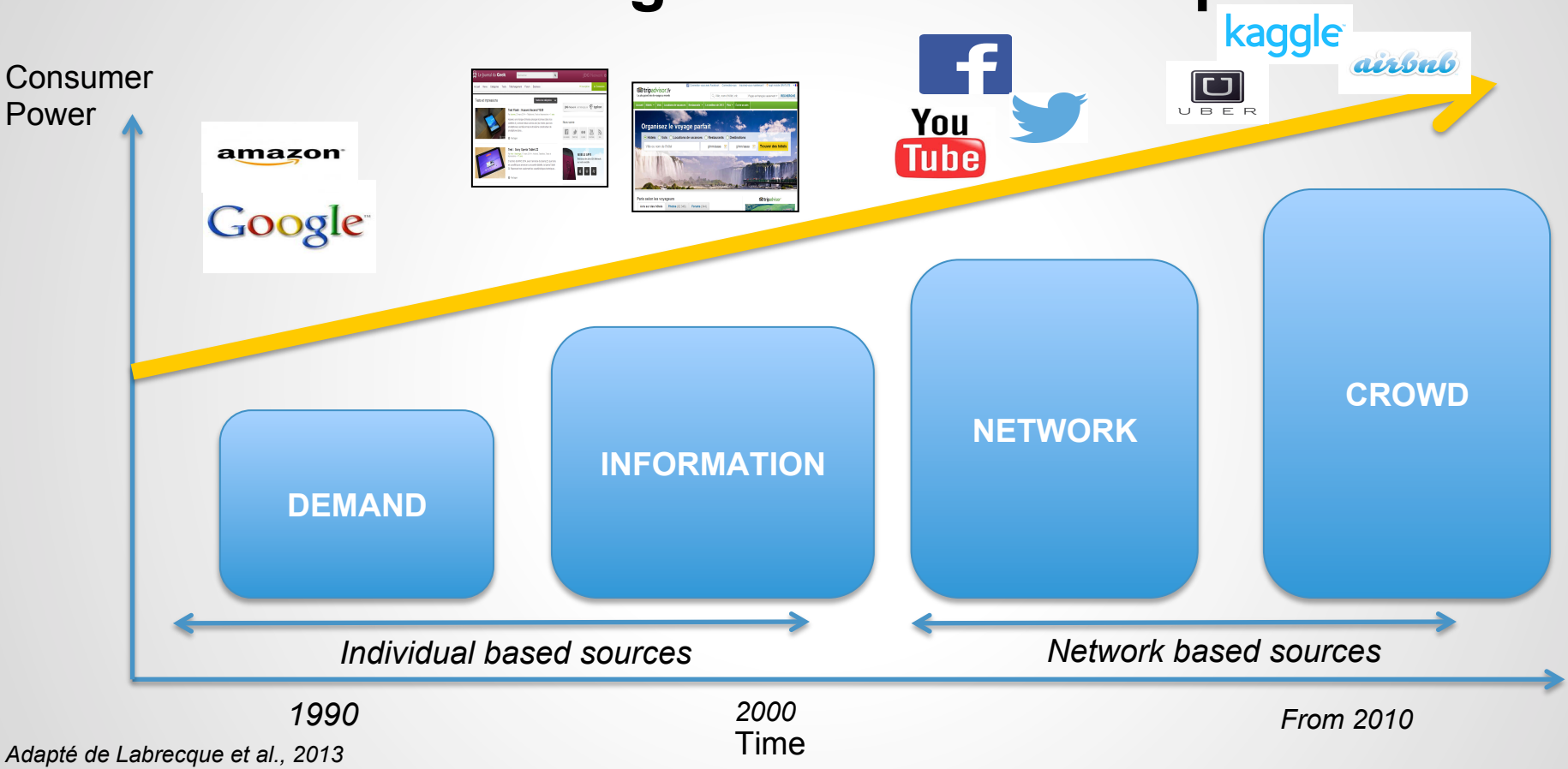
Report on national digital consultation (April 2015)

E health (June 2015)

Digitalization and data

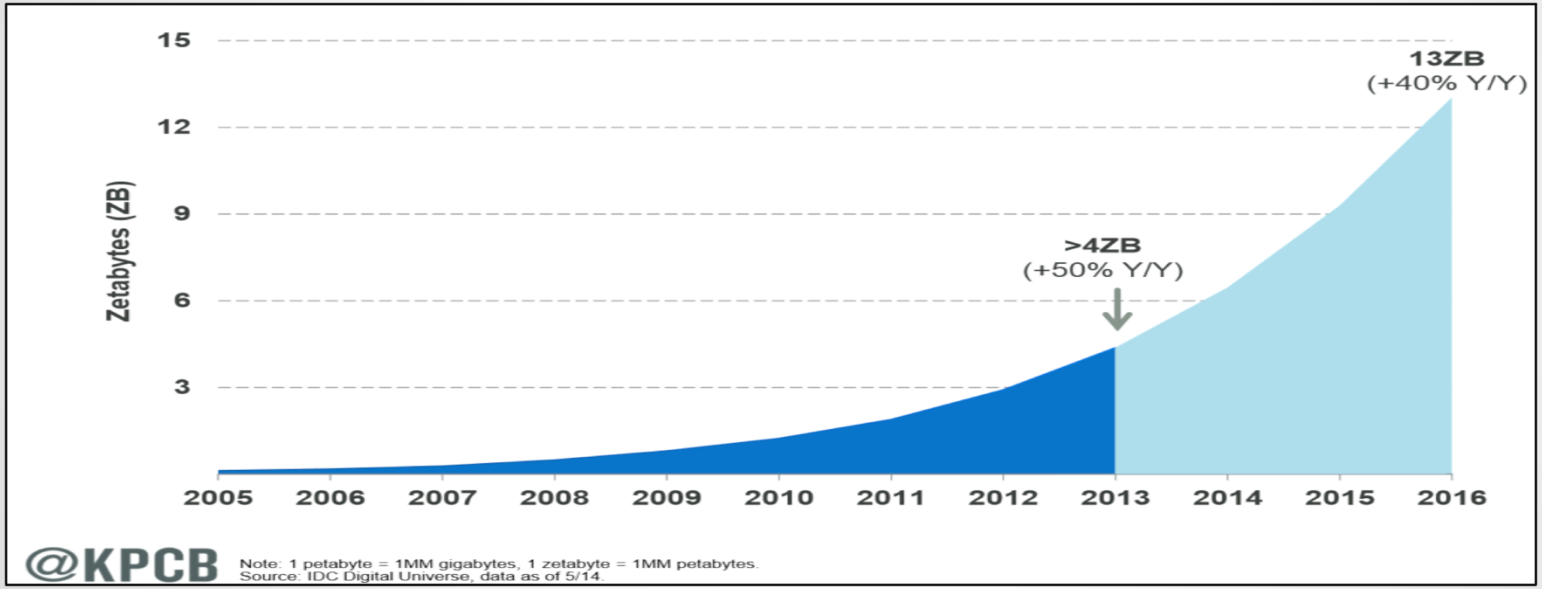
Digital metamorphosis
is not only the 3rd industrial revolution…

It is source of digital consumer empowerment



Adapté de Labrecque et al., 2013

Massive information sharing era
2/3 of digital content is created and consumed by individuals (video, text, image, social media sharing)



From Big Data to Huge Data….

Volume

Velocity

Variety

300 petabytes of data stocked on Facebook, coming from 1,35 milliard monthly active users, 3 millions of messages sent every 20 minutes

More that **6 billions of videos seen every month on You Tube**

58 millions of tweets written every day; 2,1 billions of researches every day on Twitter

Smartphone US users between 18 and 24 years send in average more than **2000 messages** by month and receive more than 1800

IP traffic in the world X 5 in the next 5

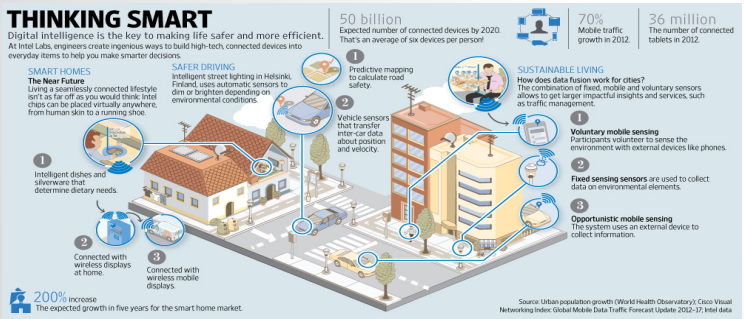
More than 50% of the traffic will come from non PC devices in 2018

Mobile data traffic x 11 in 2018

1000^8	10^{24}	*Yotta*	Y
1000^7	10^{21}	*Zetta*	Z
1000^6	10^{18}	*Exa*	E
1000^5	10^{15}	*Péta*	P
1000^4	10^{12}	*Téra*	T
1000^3	10^9	*Giga*	G
1000^2	10^6	*Méga*	M
1000^1	10^3	*Kilo*	k
$1000^{2/3}$	10^2	*Hecto*	h
$1000^{1/3}$	10^1	*Déca*	

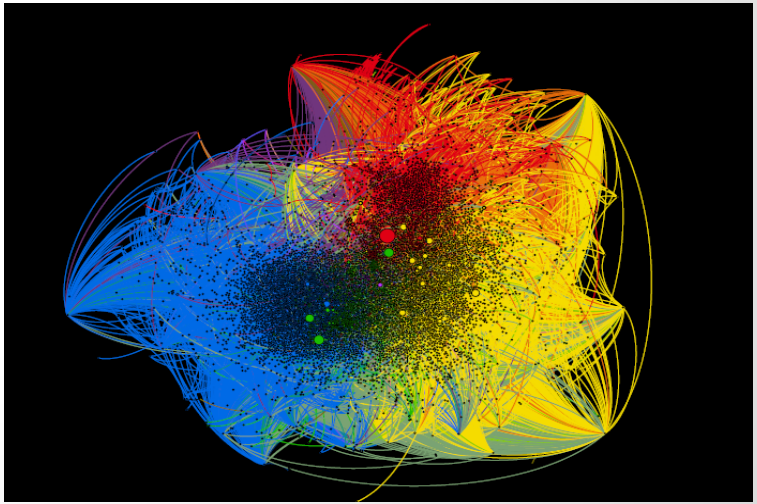
A new paradigm

Our lives in data



Big Data management

- Collect data
- Aggregation of data coming from different sources
- Analysis:
  - Understand
  - Detect weak signals, optimize
  - Trace
  - Predict



2 visions for Big Data

INDUSTRY

TECHNOLOGIES
(VOLUME, VELOCITY, VARIETY)

DATA SCIENCE

BUSINESS & JOBS TRANSFORMATIONS

SOCIETY:

TRACES

SURVEILLANCE

ALGORITHMS

Data challenge in health sector:

Situation

- The global health sector and the actors generate volumes of data
- The value of these data is immeasurable in terms of economy, research, improvement of health policy, sharing.

But data exploitation implies

- Concerns for individual rights
- Concerns for professionals in health sector (decisions automatization, predictive medicine)

Consequences

- Patient rights
- Professional new skills

Data regulation: 2 principles

Conseil d'Etat, Sept 2014

- Protection of fundamental rights of individuals:

1/ Passive consent of individuals is a barrier to effective protection

- Complex CGU often not read
- Privacy paradox

2/ Actual rights give few power to individuals

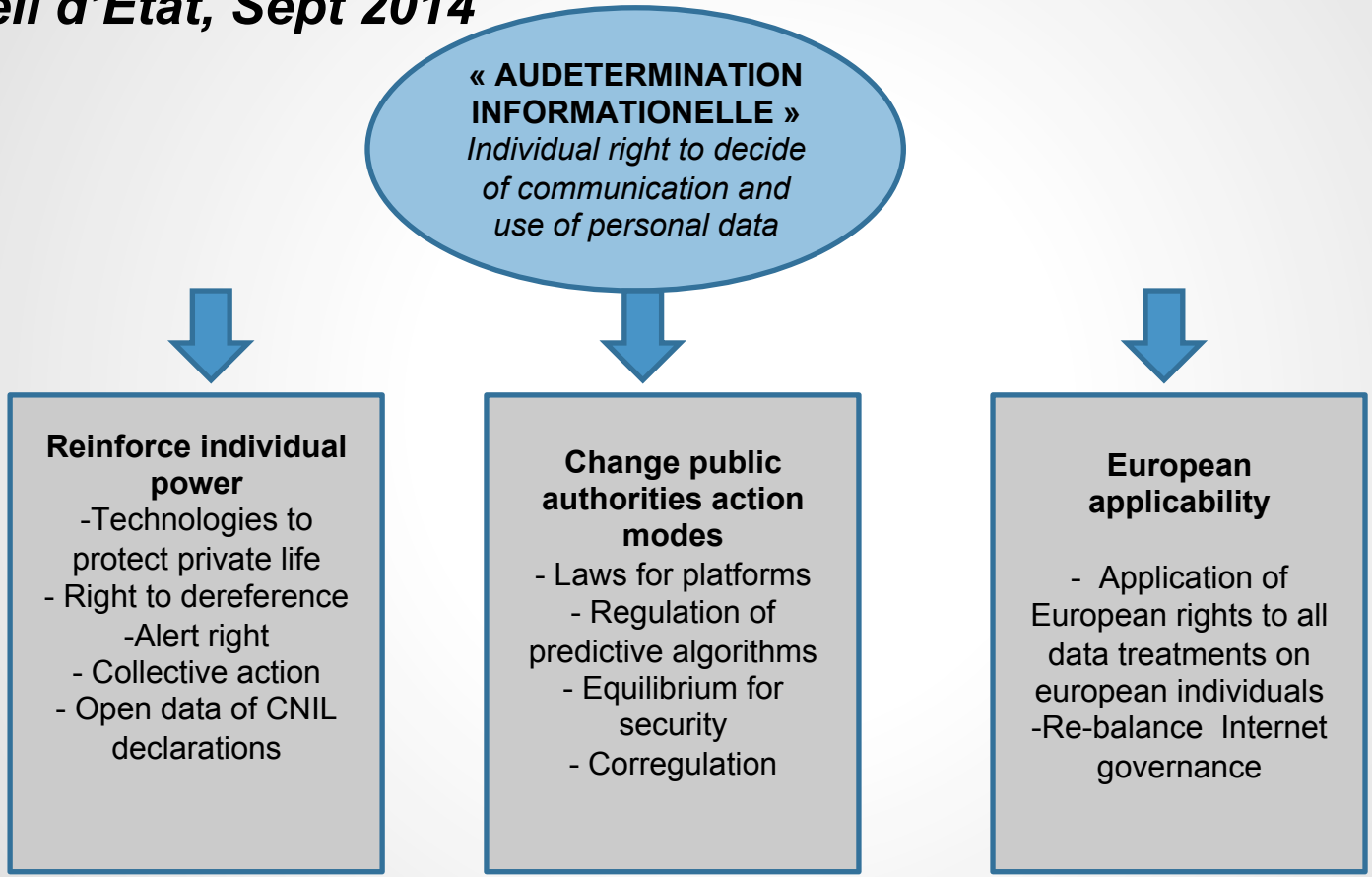
- No negociation for confidentiality
- Same rules for the dominant platforms

3/ Exclusion of data property in personal data protection

- Digital at the service of public good

The « autodétermination informationnelle » principle

Conseil d'Etat, Sept 2014



Patients data management

US BLUE BOTTON

Having secure, electronic access to view and download your health records online means you can:
- Share your information with people you trust, like your family doctor, specialists, and caregivers
- Check your information to make sure it is correct and complete
- Keep track of important health information like medications, vaccination records and test results
- Have your medical history available if you are changing doctors or visiting a specialist
- Find specific information about your health and healthcare when you need it, like in an emergency situation or when you are traveling out of town away from your usual healthcare providers

PIMS

Fing fondation internet nouvelle génération

Self Data project

Data sharing supposes to have:

- Interoperability and portability standards
- Anonymization
- Security of environments, no circulation through the Net
- Authorization for access, segment by segment of data
- Explicit consent, readibility and clarity for patients

Health data sharing for public good

- To adopt a case by case approach to open data, because a data is linked to a context and a finality
- To allow public actors to ask for constitution of « public good » data coming from public actors
- To promote organisations having « public good » data to share them

Ex: Openstreetmap for Ebola

(Croix Rouge US, MSF Suisse)

Commons (1)

- Activities of organized communities regulating themselves in order to protect and develop ressources

Ex: wikipedia, open source

- Digital commons are source of economic and social innovation, at the center of the movement of Open data
- Development of commons creates cooperations between public actors, private companies, contributors
- Ex: IGN, La Poste and OpenStreetMap for the constitution of BAN (Base Adresse Nationale)

Commons: the challenges (2)

- To promote public actors participation to commons creation

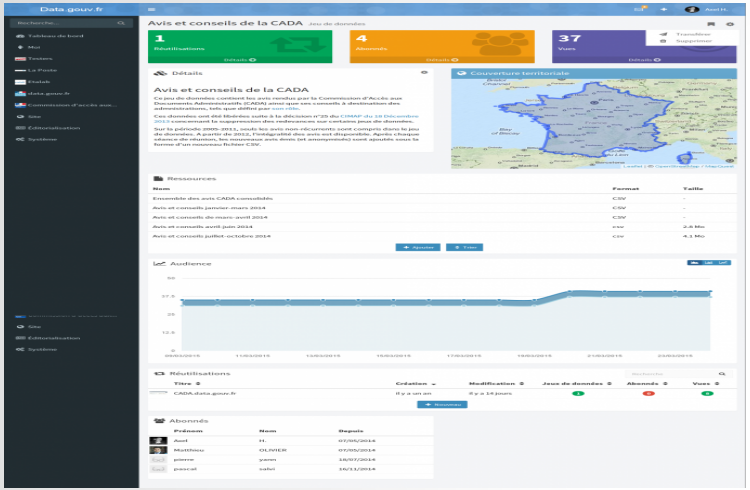
- To understand open licences (Creatice commons (CC), general public Licence (GPL), Open database (ODBL))

- To define policies to share contents produced by collectivities and public actors

Ex: Education sector

Open education with re-usable contents: Open education, Khan academy, sesamath, FUN, openclassroom,…..

Open data in France



PSI Directive, 27 Juin 2013

Public data sharing

Danemark: Basic data for everyone (2012)

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RAPPORT SUR LA GOUVERNANCE ET L'UTILISATION DES DONNÉES DE SANTÉ

Pierre-Louis BRAS, inspecteur général des affaires sociales
avec le concours d'André LOTH, administrateur général, directeur de projet à la DREES

Challenge : to train health sector professionals to digital litteracy

➢ Digital challenges: relationship patient-doctor, peer to peer communities, telemedecine, quantified self, robotization, decision making (Watson), new actors (Google, Apple,…), augmented human being, Internet of Things, transhumanism….

➢ Digital skills

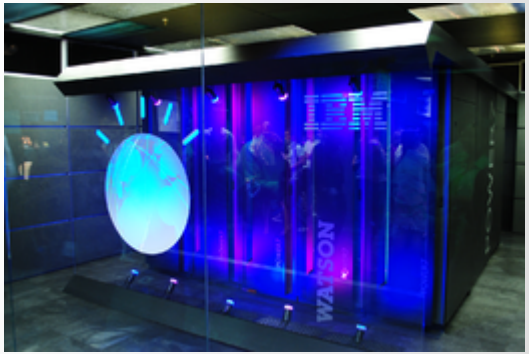
- Digital litteracy
- Computer science education

Ethics & algorithms

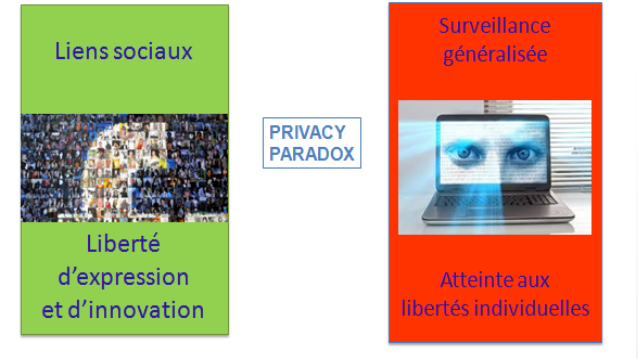
Machine Learning

Prédiction

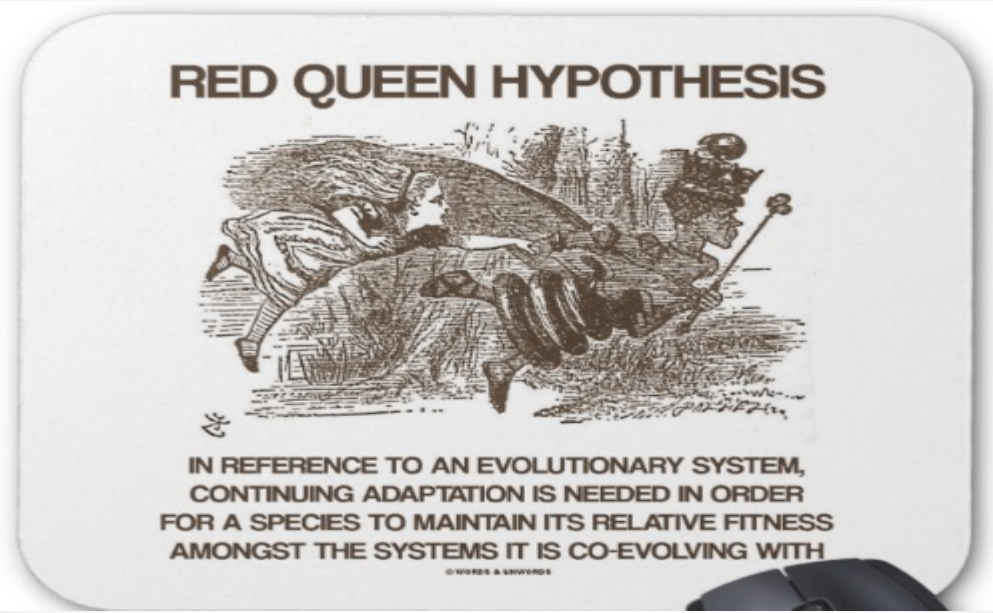
Recommandation



ETHICS ?



Data management & data sharing
The red queen hypothesis…



Organisms must constantly adapt, evolve, and proliferate not merely to gain reproductive advantage, but also simply to survive while pitted against ever-evolving opposing organisms in an ever-changing environments

Merci de votre attention
@balague

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